Out of the Shadows:
Engaging the Family in Substance Use Disorder
Prevention, Treatment, and Recovery

Alicia S. Ventura, MPH
Boston Medical Center
May 2, 2019
@AliciaSVentura @TheBMC
I have no relevant conflicts of interest to disclose
OBJECTIVES

To understand:

1. Prevalence of affected family members (AFMs)
2. Impact of substance use on family system
3. Stigmatization of families impacted by substance use
4. Family members as agents of change
5. Actionable steps toward family-centric models of care
Family members:

individual's closest emotional connections

- Defined by members
- Provides emotional, physical, financial support
- Own unique culture
- Examples: partners, parents, siblings, grandparents, aunts, uncles, cousins, friends “like family”, street families
“Addiction has been characterized as a “family disease” since the mid-twentieth century. That rhetoric continues today, but there is little evidence that such beliefs permeate clinical practice. If we really believed that addiction was a family disease, we would not assess, treat and provide continued support services to individuals in isolation from their families. We would instead deliver family-oriented models of engagement, assessment, treatment and continuing care.”

-William White

WHAT CAUSES A SUBSTANCE USE DISORDER?

Just a quick recap!
GENETICS ACCOUNT FOR 50-75% OF ADDICTION
EXPERIENCES IN CHILDHOOD ALSO IMPORTANT RISK FACTORS

Association between ACEs and Negative Outcomes

ACEs have been found to have a graded dose-response relationship with 40+ outcomes to date.

Risk for Negative Health and Well-being Outcomes

# of ACES

0 1 2 3 4 ≥5

*This pattern holds for the 40+ outcomes, but the exact risk values vary depending on the outcome.


© Boston Medical Center 2019
NO SINGLE FACTOR CAN DETERMINE WHETHER A PERSON WILL DEVELOP A SUBSTANCE USE DISORDER

Some contributing factors:

- Genetics
- Structure of brain
- Psychological influences
- Environmental influences
- Age of first substance use
A SUBSTANCE USE DISORDER IS NOT JUST ONE THING

Simplified views of addiction can harm public health efforts and increase stigma

✓ Brain changes impair one’s ability to make rational and consistent choices despite negative consequences

✓ A substance use disorder does not eradicate free will

✓ People with substance use disorders can and do exert self control. However, this control is often opposed by overpowering impulses
PREVALENCE OF AFFECTED FAMILY MEMBERS AND HEALTH OUTCOMES
IN THE US, THE NUMBER OF FAMILY MEMBERS AFFECTED BY A LOVED ONE’S ALCOHOL OR DRUG USE IS >60 MILLION


https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=PEP_2018_PEPANNRES&src=pt
Some estimate approximately 1 in 2 people have a relative or close friend with a substance use disorder (SUD).

Pew Research Center, October, 2017, “Political Typology Reveals Deep Fissures on the Right and Left”

© Boston Medical Center 2019
FAMILIES LEFT TO BEAR COLLATERAL CONSEQUENCES OF CURRENT ADDICTION EPIDEMIC
ANNUAL DEATHS FROM OVERDOSE VS. OTHER MAJOR CAUSES

The number who die each year from...

- **Drug overdoses**: 64,026
- **Car accidents**: 40,200
- **Guns**: 38,440
- **H.I.V.**: 6,138

New York Times, Just How Bad is the Drug Overdose Epidemic? 10/26/2017
NEW MOTHERS WITH OPIOID USE DISORDER AT HIGH-RISK FOR FATAL OVERDOSE
(MA State Data 2011-2015)

321 times higher for mothers with OUD


27 times higher for mothers of infants with NAS

© Boston Medical Center 2019
2/3 of incarcerated parents locked up due to non-violent drug offenses

Significant racial/ethnic disparities exist among 2.7 million children with 1 or more incarcerated parent

1 in every 28 children or 3.6% of US population under 18 has 1 or more parent living behind bars.

SUBSTANCE USE ALMOST ALWAYS GIVES RISE TO FAMILY CONFLICT

SIGNIFICANT INCREASES IN CHILDREN ENTERING FOSTER CARE SYSTEM

Children in foster care by state from 2014-2018

Many of the states hit hardest by the opioid crisis experienced significant increases in children entering the foster care system between 2014 and 2018.

% change 2014 vs. 2018

- >20%
- 0 to 20%
- 0 to -20%
- > -20%
- no data

Source: HHS, state agencies
EXTENDED FAMILY MEMBERS FORCED TO TAKE ON NEW ROLES AS PRIMARY CAREGIVERS

For every 1 child in foster care with relatives there are 20 children being raised by grandparents or other relatives outside of the foster care system.

Children in Out of Home Care With Alcohol or Drugs as a Reason for Removal

- Foster Care (Relative): 40%
- Foster Care (Non-Relative): 30%

Children in Foster Care With Relatives Due to Alcohol or Drug Abuse

- Percentage of Relative Foster Children
- 33.7% '08
- 34.3% '09
- 37.6% '10
- 35.9% '11
- 40.1% '12
- 39.7% '13
- 40.4% '14

**Potentially stressful objective event:**
One which may lead to conflict, frustration, change or pressure

**Sensitive cognitive appraisal:**
Personalized perceptions of threat, influenced by familiarity of event, its controllability and its predictability

**Emotional Response:**
annoyance, grief, anxiety, depression, fear, rejection, grief

**Physiological response:**
autonomic arousal, hormonal fluctuations, neurochemical changes, etc.

**Behavioral response:**
coping efforts, such as lashing out, blaming oneself, seeking help, solving problems and releasing emotions
Study of Kaiser’s administrative records (3.2 million members)

Compared to controls, both adult and child AFMs had greater per person total healthcare costs 2 years before, and 1 year before family member using alcohol or other drugs made contact with health system.

© Boston Medical Center 2019
Prevalence of medical and mental health conditions in the year before the index date: Family members of AODD persons compared to family members of non-AODD primary care utilizers.

<table>
<thead>
<tr>
<th>Medical/Mental Health Conditions</th>
<th>Number (Percent) of persons receiving medical diagnoses during year</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adults (N=26204)</td>
<td>Adults (N=27364)</td>
</tr>
<tr>
<td>Acid related disorders (GAS01, GAS06, GAS08)</td>
<td>1740 (6.6)</td>
<td>1857 (6.8)</td>
</tr>
<tr>
<td>Asthma (ALL04, ALL05)</td>
<td>1472 (5.6)</td>
<td>1536 (5.6)</td>
</tr>
<tr>
<td>Attention deficit disorder (PSY05)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Depression (PSY09)</td>
<td>1571 (6.0)</td>
<td>1023 (3.7)</td>
</tr>
<tr>
<td>Diabetes (END06–END09, EYE13)</td>
<td>1359 (5.2)</td>
<td>1539 (5.6)</td>
</tr>
<tr>
<td>Hypertension (CAR14, CAR15)</td>
<td>3396 (13.0)</td>
<td>3454 (12.6)</td>
</tr>
<tr>
<td>Lower Back Pain (MUS14)</td>
<td>2926 (11.2)</td>
<td>2774 (10.1)</td>
</tr>
<tr>
<td>Otitis media (EAR01)</td>
<td>990 (3.8)</td>
<td>1072 (3.9)</td>
</tr>
<tr>
<td>Pneumonia (RES02)</td>
<td>1402 (5.4)</td>
<td>1273 (4.7)</td>
</tr>
<tr>
<td>Substance use disorders (PSY02)</td>
<td>1091 (4.2)</td>
<td>577 (2.1)</td>
</tr>
<tr>
<td>Trauma (EYE12, GSU12, MUS02, MUS04, MUS08, MUS09, NUR15, NUR16, REC03, REC04, SKN01)</td>
<td>4300 (16.4)</td>
<td>3918 (14.3)</td>
</tr>
</tbody>
</table>

*Odds ratio from logistic regression adjusting for gender, age, age-squared, income (in quintiles based on median family income by census block group from the 2000 US census), primary facility where member received care, family size (as a categorical variable), gender of the index person, role of the index person (subscriber, spouse or dependent), and cost of the index person in the year before the index date.

Comparison of cost, utilization and diagnoses of families affected by 3 chronic conditions:

1. Substance Use Disorder
2. Asthma
3. Diabetes

• ALL family members most likely to be diagnosed with condition related to that of index family member

• Family members of SUD index patients:
  • More likely to be diagnosed with SUDs, depression and trauma than diabetes or asthma family members
  • Higher costs than both asthma and diabetes family members, 2 years prior and year prior to initial diagnosis of index patient

Impact is variable – **largely mediated by resiliency**!

Risk of adverse effects is greatest if both parents have SUD

- SUD can impede ability to provide nurturing environment and consistent attachment

Increased risk for:

- Abuse or neglect, leading to involvement in the child welfare system
- Physical and mental health problems
- Social skill deficits
- Oppositional behaviors
- Academic problems (e.g., lower grade point averages)

IMPACT OF SUBSTANCE USE ON FAMILY SYSTEM
“Fortunately, you weren’t screwed up by a dysfunctional family. You were screwed up by a functional family.”
FAMILY IS A SYSTEM:
GOAL IS TO FUNCTION LIKE A FAMILY


© Boston Medical Center 2019
FAMILY SYSTEMS THEORY:

HOMEOSTASIS
FAMILY SYSTEMS THEORY:

FEEDBACK
FAMILY SYSTEMS THEORY:

BOUNDARIES
SUBSTANCE USE DISORDER DISRUPTS FAMILY SYSTEM AND RELATIONSHIPS WITH INDIVIDUAL MEMBERS

- Impacts stability of home, family unity, mental and physical health, finances, and overall family dynamics
- **Results in unusual levels of stress**
- Increases risk of interpersonal violence, child abuse, and other traumatic experiences
- Social support needed but often fails
- Professionals in position to help often have no or misinformation, or view family as barrier to treatment
IMPROVING FAMILY RELATIONSHIPS IS THE TARGET FOR CHANGE
STIGMATIZATION OF FAMILIES IMPACTED BY SUBSTANCE USE
“Stigma against addiction in the health care system is rooted in a historical belief that addiction is not worthy of the attention of medical professionals. This has had a profound impact on creating generations of providers who are unable to identify, treat, or manage a preventable and treatable disease that is prevalent in their patient population. It also affects the quality of care that patients with addiction do receive since a shadow treatment system has filled the void left by the health care system. This system is not subject to the same rigorous standards as the health care system, does not adhere to evidence-based practices, offers substandard care to patients with a serious medical condition, and increases the risk of avoidable relapse, morbidity, and mortality.”

- Linda Richter, “Stigma and Addiction Treatment”

MANY FAMILIES ISOLATE DUE TO STIGMA

- Decreases *all* family members willingness to seek treatment\(^1\)
- Delays seeking help more than structural barriers such as financial insecurity\(^2\)
- Family members more likely to be viewed as primary cause of drug use and relapse\(^3\)
  - Parents viewed as responsible
  - Children viewed as contaminated

---


© Boston Medical Center 2019
Clinical and Psychometric Characteristics of the Wives of Alcoholics

By JOHN B. RAE and ALAN R. FORBES

has married five. What are they persistently seeking? The answer to a need of their own. Whelan describes four kinds of wives who marry alcoholics or potential alcoholics to meet their own needs. Their names will define them: Controlling Catherine, Suffering Susan, Punitive Polly, and Wavering Winifred. Fox refers to types of husbands of alcoholics as the long-suffering martyr who mothers and spoils his child wife, the husband who leaves furiously but comes running back, the unforgiving and self-righteous husband, and the punishing, sadistic variety.” In our offices, after an initial actual

Family Relationships Contributing to Alcoholism


From such latter observations the concept of the classical “alcoholic’s wife” has emerged as one hostile to men, with unconscious conflict regarding her own sexuality, projecting her inadequacies on to her husband and finding in his alcoholism a defence against awareness of her own conflicts (Futterman, 1953). Reports
POPULARIZATION OF THE CO-DEPENDENCY MOVEMENT
HISTORICAL PRECEDENT FOR FINANCIAL EXPLOITATION OF FAMILY MEMBERS...
...CONTINUES IN PRESENT DAY AMERICA

The addict brokers: Middlemen profit as desperate patients are ‘treated like paychecks’

By DAVID ARMSTRONG and EVAN ALLEN — BOSTON GLOBE / MAY 28, 2017

After Addiction Comes Families’ Second Blow: The Crushing Cost of Rehab

Out-of-pocket expenses to save loved ones are soaring beyond what many can afford, especially when addicts go through multiple rounds of treatment

Michelle Vandercar and Jake, one of three sons battling addiction. BENJAMIN ZACK FOR THE WALL STREET JOURNAL

Inside The $35 Billion Addiction Treatment Industry

Reports Of Rehab Scams Raise Concerns About Addiction Treatment Quality

Dan Munro Contributor
Pharma & Healthcare
I write about the intersection of healthcare innovation and policy.

90.9 wbur

© Boston Medical Center 2019
Not including family members in treatment decisions

Not allowing family members to make appointments / schedule initial intake visits (insisting patient call)

Ignoring information about patient history

Not acknowledging extent of care family provides at home

Assuming family’s role in disorder is primary

Limiting information sharing beyond what is required

Pathologizing parents attempting to be involved in care
Is there a "blackout" period?
Yes. The "blackout" period, during which residents are not permitted to have visitors (except underage children), make phone calls, go on passes, or send and receive mail, covers the first 30 days of treatment.

Additional UHC Visiting Hours

- **Intensive Care Unit**: 9 - 9:30 a.m., 1 - 1:30 p.m., 4 - 4:30 p.m. and 8 - 8:30 p.m. Family is allowed in the Waiting Area (fourth floor) at all times. No one under the age of 10 will be allowed in the unit.
- **Emergency Room**: Every 2 hours for 10 minutes. Visitation will remain flexible and at the discretion of the ER personnel based on patient volumes.
- **Medical Detox Unit**: Tuesday & Thursday from 4 - 5:00 p.m. after patient has been admitted for 72 hours. Visitors must check-in and speak to counselor at 3:00 p.m. the day of visitation.
FAMILY MEMBERS AS AGENTS OF CHANGE
1. Affected family members (AFMs):

- At high risk of developing chronic health conditions; deserving of care in own right
- Likely to seek care before person using substances (average 6-10 years)
- Indirectly influence behavior of person using substances
WHY INCLUDE THE FAMILY IN ADDICTION TREATMENT?

2.

- Improves outcomes for all family members
- Improves patient engagement, retention in care, and sustained recovery
- Improves substance use outcomes
- Reduces risk of relapse and fatal overdose

© Boston Medical Center 2019
FAMILY MEMBERS ARE ALLIES. LET’S ENGAGE THEM!

Family members typically first to seek help for themselves and their loved ones for long periods of time

Point of entry into improving health for entire family

Advice given to family members can impact health of person with addiction (sometimes in indirect ways)

Engaging family member in appropriate treatment will help improve outcomes for all other family members
RELATIONSHIP BETWEEN NEGATIVE LIFE EVENTS AND SUBSTANCE USE REDUCED BY HIGH FAMILY SUPPORT

N=1,289 students age 11-13 from Bronx and Manhattan, NYC

ADVICE AND EDUCATION GIVEN TO FAMILY MEMBERS IS IMPORTANT
To recover, first need to hit rock bottom

Showing kindness “enables” substance use

All family members are “co-dependent”

Families are powerless against a loved one’s SUD

Tough love is the best approach
Result of failure to equip families with needed education and resources

Number of petitions filed in MA to have a person civilly committed due to alcohol or drug use 2010-2018

~80% of petitions are filed by family members

Judge Rosemary Minehan. Excerpt from presentation on MA Civil Commitments: MA Trial Court delivered to MA Department of Public Health Section 35 Commission. Dec 5, 2018.
CATEGORIES OF EFFECTIVE FAMILY INTERVENTIONS: PURSUIT OF EMPOWERMENT AND SUPPORT

1. Intervention/counseling with individual family member to engage treatment resistant individual in care (e.g., CRAFT)

2. All family members engage in treatment such as education groups, multifamily groups, individual family, or couples therapy sessions (e.g., MDFT)

3. Help family members address their own concerns, problems, and emotions (e.g., 5-Step Method)

Typical model employed in US: primary focus on individual with SUD with limited family involvement

COMMUNITY REINFORCEMENT AND FAMILY TRAINING (CRAFT)

- Core assumption is that AFMs are not powerless
- Structured sessions to educate AFM to change their own behavior with end goal of engaging treatment resistant individuals in care
- Based on theory that environment is important to promotion of treatment entry and reduction of AFM stress
- Reward positive changes to create environment that *invites change instead of demanding it*
- CRAFT or CRAFT-informed services becoming more widely available (e.g., online versions, groups)

CRAFT COMPARED TO AL-ANON AND JOHNSON INSTITUTE INTERVENTION

Systematic review identified 4 high quality RCTs, CRAFT:

- **3.25 X** more effective than Al-Anon at treatment engagement
- **2.15 X** more effective than Johnson Institute Intervention at treatment engagement
- Improvement in family and individual health
- Reduction in substance use, regardless of treatment initiation

5-Step Method: Identifying sources of support

ACTIONABLE STEPS TOWARD FAMILY CENTRIC MODELS OF CARE
IF WE ONLY FOCUS ON THE INDIVIDUAL, WE ARE MISSING MOST OF THE PICTURE
A STARTING POINT: UNIVERSAL SCREENING TO IDENTIFY AFMS

- High utilizers of healthcare system
- Likely to make contact with healthcare system first
- Likely to know about substance use first
  - Opportunity to intervene early

☑ Are you concerned about the drinking or drug use of anyone in your household?
A STARTING POINT: ENGAGE, EDUCATE, AND WELCOME FAMILY MEMBERS

- Identify available resources; assess what is feasible
- Engage and welcome any family members
- Create a family welcome brochure: explain program, any family-specific resources, role family members will play
- Educate families on evidence-based treatments for addiction
- Offer written materials on impact of substance use on families and additional community supports (vetted)

**Families may be overwhelmed at initial visits, offering educational resources they can take home and read later can be helpful**
A STARTING POINT: FACILITATE FAMILY INVOLVEMENT, SOCIAL SUPPORT

- Ensure family has naloxone and knows how to respond to overdose
- Encourage patient to sign release for family involvement at first visit and moving forward, discuss the importance of social support
- Routinely ask about family involvement
- 42 CFR Part 2 does not restrict information family can give to provider
- Family members grieving death of a loved one require different supports than those affected by active substance use
POTENTIAL PITFALLS TO KEEP IN MIND

- Not enough buy-in at the top
- Insufficient resources
- Adding family support to existing work loads
- Viewing family engagement as ancillary and not essential
- Entire team not seeing family involvement and support as part of their role
- Confidentiality concerns
Families need to be supported to make the best decisions they can, in the circumstances they are in, with the resources they have available.
THANK YOU!

alicia.ventura@bmc.org
@AliciaSVentura @TheBMC
EXTRA SLIDES
MULTIDIMENSIONAL FAMILY THERAPY (MDFT)

- Comprehensive, family-centered treatment for teens and young adults
- Simultaneously addresses substance use, mental health disorders, and other problematic behaviors
- Flexible, can be integrated into wide range of programs

EVIDENCE OF MDFT’S SUCCESS

YOUNG ADOLESCENT STUDY


5-STEP METHOD

• Focus on affected family members
• AFMs are ordinary people attempting to respond to highly stressful experiences

The 5 steps

1. Let family member talk about problem – explore stress and strain
2. Provide relevant information
3. Explore how family member responds to loved one’s substance use
4. Explore and enhance social support
5. Discuss appropriate referrals for specialist help

5-STEP METHOD:
PROFESSIONAL INTERVENTION VS. SELF-HELP MANUAL
(n=143 family members)

- No difference in outcomes b/w professional delivered and manual
- Improved coping, symptom rating, and impact of substance use on family b/w baseline and 12-months
- Perceived decrease in loved one’s substance use
- Affected family member improved regardless of:
  - Perception of change in loved one’s substance use
  - Number of years family had lived with substance use
    - Average: 9.5 years; Max: 35 years